

Toolkit for Caregivers



welcome

WELCOME TO THE SELECTIVE MUTISM ASSOCIATION'S TOOLKIT FOR CAREGIVERS!

This toolkit, developed by members of the Selective Mutism Association (SMA), is meant to serve as a helpful guide for caregivers of youth with selective mutism (SM).

Within these pages, you will find useful information, tips and strategies, and assorted resources to help you best support individuals diagnosed with SM. We hope that you find this toolkit informational and valuable. Feel free to share it with any other family members and friends who may benefit from it.

If you would like information to share with teachers and school personnel, please also see SMA's "Toolkit for Educators," available on our website.

If you would like more information on selective mutism and the work of the Selective Mutism Association, please visit **www.selectivemutism.org**.

Please note this toolkit was written by the Selective Mutism Association; all authors live in the United States and the information contained within is directly applicable to the mental health and education systems in the United States. Originally written in English, this document has been translated into multiple other languages. Individuals reading a translated Caregivers' Toolkit who are from other countries should take into account that there are differences in countries, cultures, and education systems and that may impact the relevance of this information.

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what is selective mutism?

Selective mutism (SM) is an anxiety disorder in which an individual is unable to speak in some settings and to some people because of anxiety. It affects approximately 1% of youth, though more research is needed to better understand how common it actually is, especially among older individuals. People with SM usually are able to speak in environments in which they are very comfortable. In fact, some children with SM are even described as "chatterboxes" at home, although even speech in comfortable environments may be limited at times, particularly when visitors are present. Regardless, the individual's speech at home generally is quite different from speech in places like school, with peers, and in community settings, where they might not be able to speak at all.

The term "anxiety disorder" describes when someone is excessively fearful, anxious, worried, or nervous to the extent that these feelings cause significant distress and impairment in their life. Everyone experiences fear and anxiety periodically, but for people with anxiety disorders these emotions are stronger, last longer, are experienced more frequently, and negatively impact their ability to participate in everyday activities. For individuals with SM, this anxiety manifests in difficulties communicating when uncomfortable.

The official diagnostic criteria for SM are as follows:

- Consistent failure to speak in specific social situations in which there is an expectation for speaking (e.g., at school) despite speaking in other situations.
- The disturbance interferes with educational or occupational achievement or with social communication.
- The duration of the disturbance is at least one month (not limited to the first month of school).
- The failure to speak is not attributable to a lack of knowledge of, or comfort with, the spoken language required in the social situation.
- The disturbance is not better explained by a communication disorder (e.g., stuttering) and does not occur exclusively during the course of autism spectrum disorder disorder, schizophrenia, or another psychotic disorder.

Although the above list broadly describes SM symptoms, in daily life, this condition can manifest in a variety of ways. For example, an individual with SM might:

- · Speak comfortably and at full volume with parents and siblings when at home
- · Struggle to speak to peers, even though they want to
- Speak in a whisper at parties, in stores and restaurants, and while participating in extracurricular activities
- · Give only single word or short phrase responses in social settings
- · Rarely, if ever, speak in school, or only speak at school through a close friend
- Engage verbally with a friend or neighbor at home, but not be able to speak to the same person at school or during community activities
- Whisper responses to questions from a trusted teacher at school, but never initiate speech
- · Answer straightforward, factual questions at school, but be unable to provide more detail or to answer longer, opinion-based questions
- Be unable to get basic needs met such as asking a teacher for help, asking to go to the bathroom, or asking to go to the school nurse
- · Use gestures, sounds, or writing in place of verbal communication
- · Appear "frozen" when anxious with stiff body language and the inability to engage in non-verbal activities
- Be happy, engaged, laughing, and fully participatory in activities in every way other than speaking

SM typically first emerges in early childhood, but often it is not formally recognized until a child reaches school-age. Caregivers might not realize their child has trouble speaking around other people if talking is not a problem at home. Or, they may think that their child is "just shy," without realizing how impairing their child's anxiety really is. Therefore, caregivers are sometimes first alerted to a child's symptoms by early childhood educators who have the unique perspective of regularly seeing the child in the school setting and interacting with a range of peers.

Of note, anxiety can take many forms, and many children with SM also experience other worries and fears too. Some of the most common ways in which anxiety can present are explained in the table below.

| Anxiety Disorders | | |
|---------------------|--|--|
| Types of Anxiety | Description | |
| Separation Anxiety | Fear of being away from parents or other important loved ones and worry about something bad happening during separations (e.g., getting lost, parents getting in a car accident) | |
| Social Anxiety | Fear of being embarrassed, doing something humiliating, or being negatively judged by others | |
| Generalized Anxiety | Frequent and hard to control worries about a broad range of topics (e.g., school performance, friendships, following rules, world events, family relationships, health concerns) | |
| Specific Phobia | Fear of specific objects or situations (e.g., the dark, heights, vomiting, insects, needles, dogs) | |

Causes of SM

Selective mutism, like other anxiety disorders, is not caused by a specific thing. Anxiety disorders are due to a combination of factors including a biological predisposition to anxiety, an individual's temperament or personality characteristics, and environmental factors. More specifically, many people with SM have immediate and/or extended family members who also have experienced anxiety disorders, which suggests that SM is partially due to a shared genetic vulnerability. Individuals who develop SM also are more likely to have inhibited, slow to warm up personalities and may be more sensitive to emotional experiences. In addition, anxious behaviors are sometimes indirectly modeled by other family members. Family members often worry that "something bad" must have happened to cause their child's SM, but this is almost always not the case. There is no evidence that the development of SM is associated with trauma, neglect, or mistreatment. Furthermore, while some children with SM also display

oppositional behaviors, lack of speech in children with SM should not be misinterpreted as a child trying to be defiant or manipulative.

Caregivers often wonder if they did something that caused their child's selective mutism. We often hear from parents who share that friends, extended family members, and/or school professionals have suggested that selective mutism is somehow their fault. This can be especially frustrating and difficult to hear when parents typically are working extremely hard to do the best that they can to support their child. Please know that despite what caregivers may or may not be doing, sometimes selective mutism can still develop – much like a child with a healthy diet and plenty of opportunities for physical activity can still develop a condition like diabetes.

After SM symptoms first emerge, there is strong evidence that SM continues, at least in part, because of repeated interaction patterns that are often helpful in reducing anxiety in the short-term, but unintentionally make anxiety worse in the long-term. This phenomenon, explained more fully below, is sometimes called the cycle of negative reinforcement. Think about the following exchange that might happen while standing in line at the grocery store with a young child:

Store clerk (with a warm and friendly smile): "Oh, you look just like my son. How old are you?"

Child (now feeling anxious): Looks down. Does not respond.

Caregiver (now feeling distressed too): "Honey, did you hear the cashier? Tell her how old you are."

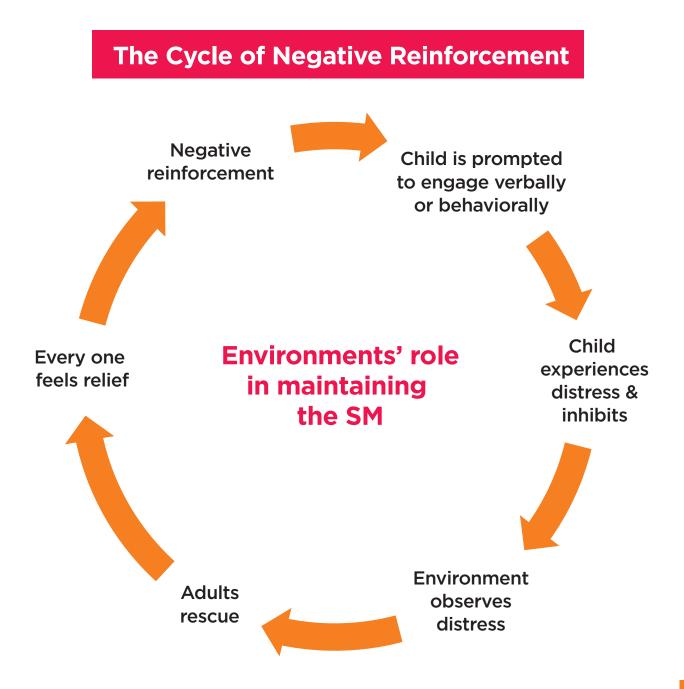
Child (now feeling even more anxious): Buries his head on his caregiver's shoulder. Still does not respond.

Store clerk (unsure of what to do): "Oh. I can see that he is shy."

Caregiver (embarrassed and apologetic): "Yes, and he is five years old."

In this situation, everyone ends up feeling uncomfortable - the child, the caregiver, and the new adult attempting to interact with the child. Ultimately, the adults "rescue" the child, keeping the conversation moving while taking away the pressure the child might feel to respond. This not only relieves the child's anxiety, but it also provides a sense of relief to the adults as well

(whether or not anyone realizes it in the moment), as everyone can move on from the uncomfortable interaction. This sequence of interactions, variations of which occur regularly with individuals with SM, reinforces patterns of not speaking. The child "practices" not answering, the caregiver accumulates more "evidence" that "rescuing" is an effective way to get through the uncomfortable moment quickly, and the same pattern is likely to be repeated the next time the child is unexpectedly asked a question. This is called the cycle of negative reinforcement because the removal of a demand (in this case the expectation of speech) reduces anxiety (thus taking away something negative or uncomfortable) and reinforces (or increases) the likelihood of the child and caregiver engaging in similar responses (not talking and rescuing) next time.



Although the example on the left included a caregiver, this pattern typically gets re-enacted many times with many different people, including teachers, coaches, grandparents, siblings, and friends. Thus, a primary goal when supporting individuals with SM is to break this cycle of negative reinforcement! Caregivers can learn new ways to support their child, not by "rescuing" them from the interaction by answering for them, but instead by starting with small, doable steps that slowly increase in difficulty and that allow a child to more independently interact and communicate with others. More information will be provided in the coming pages to help a caregiver learn how to do this.

I think my child might have SM. What should I do?

The first step towards helping your child overcome SM, is to recognize it as a problem. When a child is having difficulty with communication, it is essential to understand why so that the appropriate intervention/treatment can occur. There are many reasons why a child might be having trouble communicating, and these might include, but are not limited to, SM, a silent period while learning a second language, an autism spectrum disorder, or another language disorder such as expressive language disorder or apraxia. In addition, sometimes these conditions can occur together and/or a child with SM can be misdiagnosed. Arming yourself with accurate information about selective mutism as well as pursing a diagnosis from a treating professional who is knowledgeable about SM is necessary. If you think that your child might have SM, consider the following:

- 1. Make a list of your concerns and how they are impacting your child's life and share them with your child's pediatrician. Often pediatricians have a list of treating professionals in your local area to whom they can refer you for specialized evaluation and treatment.
- 2. Share your concerns and information regarding selective mutism with your child's teacher, school counselor, and/or special education personnel at your child's school.
- **3.** Obtain an evaluation either through a qualified treatment professional or through your child's school. SMA has a treating professional directory that lists professionals who specialize in the diagnosis and treatment of SM. In addition, schools can often conduct an evaluation; an evaluation conducted in the school environment has an educational focus and helps to determine eligibility for special education services, which may include social-emotional support for your child at school.

Research has shown that the earlier treatment is started, the easier it is to overcome SM. This may be because patterns of behavior are easier to change when they have not persisted for as long. Moreover, with early intervention, children generally are able to more fully engage in important childhood life experiences. Professionals less familiar with SM, including some pediatricians, mental health professionals, and educators, may suggest that treatment is unnecessary and advise parents to "wait a few years" for their child to "grow out of it." While this may be true for a small subset of children, many children do not quickly "grow out of" this condition, so caregivers are encouraged to find treatment and support early after selective mutism is suspected or identified.

an overview of SM interventions and treatment

Treatment for selective mutism can include therapy and medication to address the anxiety that underlies an individual's inability to speak in certain situations. Children with SM also may benefit from speech-language therapy and other interventions that may be recommended by primary treating professional(s). Although some children with SM can make gains in speaking with only family support, it is often helpful to have the guidance and expertise of a treating professional.

When considering what type of treatment/interventions to pursue for youth with SM, it is important to consider what treatments have undergone rigorous research and have been shown to be effective in improving symptoms of SM. You may hear different terms used to describe treatments that have research evidence to support them, including empirically supported treatments, research supported treatments, and evidence-based treatments. These terms all refer to the interventions that have shown to lead to the most improvement (e.g., increases in speech, reductions in anxiety, less interference associated with symptoms) in rigorous research studies. Although not every treatment works perfectly for every child, these treatments have the potential to lead to more meaningful gains more quickly; you may find yourself wasting both your time and money if you pursue less conventional treatment methods.

Evidence-based approaches for SM include behavioral and cognitive-behavioral therapies and can be delivered by clinical or school psychologists, social workers, behavior analysts, and speech-language pathologists as well as other mental health professionals. A behavioral therapy approach to SM will involve developing a step-by-step plan where the individual begins with a communication task that is within reach then gradually engages in more and more difficult speaking tasks. Another name for the process of gradually facing fears is exposure therapy. Exposure therapy is typically paired with a system of positive reinforcement to help increase motivation and acknowledge successes. A treating professional can be instrumental in guiding this process and will use (and explain) strategies such as contingency management, reinforcement, shaping, stimulus fading, systematic desensitization, exposure, social skills training, and self-modeling. Cognitive-behavioral interventions for SM can be incorporated

into treatment for children in the later elementary school years and beyond (generally ages eight and up). In addition to using the aforementioned behavioral strategies, cognitive-behavioral therapy (or CBT) also involves helping individuals recognize physical symptoms of anxiety, identify and challenge unrealistic and unhelpful thoughts about speaking (e.g., "If I speak everyone will stare at me"), and develop a coping plan to deal with anxious distress.

A professional like a psychiatrist, pediatrician, or psychiatric nurse practitioner can prescribe medications like selective serotonin uptake inhibitors (SSRIs) that address the anxiety that underlies the inability to speak in certain situations. Medications are most effective when combined with the therapeutic strategies listed above, especially to help the individuals maintain gains in communication over time. Medication is most commonly recommended when symptoms are more severe, when there is a strong family history of anxiety, and when an individual has not responded adequately to a course of behavioral/cognitive-behavioral therapy.

Speech-language pathologists (SLPs) may contribute to the treatment benefits of children with SM, especially when speech and/or language impairments co-occur with SM. SLPs also are trained in helping develop pragmatic language skills (the ability to appropriate communicate in social situations), which often is greatly impacted in children with SM. For some children, simultaneous treatment using both behavioral strategies to help children feel more comfortable speaking and linguistically-based activities to foster language development is recommended.

When trying to find a treating professional, it can sometimes be helpful to "interview" several treating professionals. Do not hesitate to ask them about their experience treating SM. The following is a list of questions you may want to ask:

- · How many patients with SM have you treated?
- · What is your treatment approach?
- To what extent are caregivers involved in treatment?
- · How will you keep track of my child's progress?
- Will there be opportunities for my child to practice speaking with other people (e.g., new adults, community members, other children) in therapy sessions?
- In what ways will you be able to support my child in reaching their goals at school?
- · What other resources would you suggest for our family?
- If you do not have experience with SM, are you open to getting consultation from someone experienced in SM to help work with my child? Are you able to attend trainings and/or do research on the condition?

For more information about how SM can be treated, please visit the Frequently Asked Questions section of our website.

quick tips for caregivers

In this section, you'll find some basic tips on how to support youth with SM in talking to new people.

1. Set a strong foundation/use "warm up" skills

- Even when caregivers and children have warm, supportive relationships, practicing "brave talking" can be challenging. Set a strong foundation for the hard work ahead by scheduling five minutes a day for one-on-one, child-led play time. Learning and using these skills can help increase your child's comfort with new people and with familiar people in new places.
- During this time, caregivers should play along with their children, describing what they are doing (like a narrator giving a play-by-play), repeating back or summarizing what they say (also known as reflection), and providing labeled praise for desirable behaviors (e.g., "Thanks so much for sharing the blocks."), without asking questions.
- One-on-one time is important with teenagers too, but will look different. Caregivers may use less narration and reflection and labeled praise should be developmentally appropriate. An important aspect of this time with kids of all ages, but especially teens, is for the caregiver to avoid any teaching, correction, or criticism. This is a time for the caregiver to connect with and follow the teen's lead. Shared activities should be based on the teen's interests and may include things like playing a video game, watching YouTube videos, or engaging in an activity around a teen's hobbies.

| Foundational or "Warm Up" Skills | | |
|----------------------------------|--|--|
| Reminders | Notes | Examples |
| The activity should be child led | Let your child choose (within reason) what to play with; refrain from jumping in and taking control of the activity. This helps increase their sense of control, which is important for children who are anxious. | Activities that are a good fit for this type of one-on-one time include arts and crafts, building toys, and imaginative play toys. For younger child try to stay away from anything that can get too messy or games with pre-set rules. Good activities for older kids include puzzles, drawing, sports, or even video games. |
| Provide labeled praise | Labeled praise lets your child know what they are doing well. It can be particularly helpful to focus it on pro-social behaviors like sharing toys, staying calm if something upsetting happens, and verbal communication. | "Thank you for remembering to put the cap back on the markers." "I love how carefully you put your doll into the crib." "You did an amazing job drawing so many small details on this picture." "Thank you for telling me that you want to use the Legos next." "You explained the rules of this game so clearly. Thank you for telling me what to do next." |

| Foundational or "Warm Up" Skills | | |
|---|--|--|
| Reminders | Notes | Examples |
| Reflect what your child says | Reflections let your child know that you have heard what they have said and that you are listening to them. They show your engagement in the interaction. | "You said that you put all of the blue blocks in a pile." "Thanks for telling me that you are coloring the house first." "You want to play basketball. Good choice." |
| Play along with your child; engage in the activity together | Play with your child, doing what they do, rather than simply watching or taking the lead. This helps them feel good about the choices they've made and helps build positive building connections. | Build a tower, make a beaded bracelet, color a picture, shoot baskets, try a video game you've never played beforedo whatever your child is doing! |
| Describe your child's actions | Providing behavioral descriptions or narrating your child's activities shows that you are engaged and paying attention to your child. For younger children, this strategy also has the added benefit of facilitating vocabulary development. | "You are lining up all of the cars for the race." "You are using the pink beads and the red beads to make a pattern." "You are starting the puzzle by finding all of the edge pieces." |

| Foundational or "Warm Up" Skills | | |
|---|--|---|
| Reminders | Notes | Examples |
| Don't ask questions | We suggest avoiding questions during these relationship building and warm up play periods because they can take the lead away from the child and depending on the circumstances may unintentionally trigger increased anxiety. | Caregivers often report that not asking questions too early is one of the hardest strategies to remember! It seems straightforward, but usually requires some practice! |
| Stay positive and enjoy the interaction | Refrain from giving corrective feedback - even if your child makes a mistake – or saying anything critical during this time. There will be opportunities for that later. Instead, focus on enjoying doing something together! | Smile, make eye contact, show affection, give high fives, tell your child that you are having fun together |

This table provides reminders and a brief explanation of the skills that will help you set a strong foundation for helping your child practice brave talking. Practicing them at home – even if your child can speak easily to you in this setting – can help you strengthen your relationship with your child. Importantly, it also will increase your comfort and confidence in using these skills to help your child warm up in more anxiety producing situations.

2. Create a step-by-step plan

- It will be easier for your child to talk to some people, while others might be much harder. With your child's input, if appropriate, make a list of the people (e.g., friends, family members, teachers, babysitters, coaches) with whom you'd like your child to be able to speak and places (e.g., playground, restaurants, soccer practice, neighbor's house) where you'd like your child to be able to speak.
- · Using your observations and your child's input, categorize these into groups such as "easy, medium, and hard." First work on easier goals, and as your child experiences success move on to harder targets. Involving your child in the creation of a speaking plan can help motivate them and give them a sense of control.
- For some, categorizing might be too difficult from a developmental perspective and for others, thinking and talking too much about speaking goals may elicit too much anxiety for the conversation to be very productive. If this is true of your child, consider giving them 2-3 choices about potential practices and let them pick the one that they'd most like to work on.
- It may be helpful to think about the steps of your plan like steps on a ladder; the first steps are relatively easy to achieve, but as you "go higher" the steps will becoming more and more challenging.
- Remember to start small! You can't start climbing a ladder from the top rung! For some youth, the first steps of their plan may not involve directly talking to a new person, but rather talking to caregivers in new places or in front of new people. In other cases, sharing videos of your child talking may be a helpful step to prepare your child to actually speak to someone new.
- Slowly build on your child's successes. When they have mastered one step (for example, speaking to their teacher in an empty classroom), change one variable at a time. For example, the next step might be speaking to a new teacher in the same empty classroom (changing just the person, but keeping the location the same) or the same teacher in the hallway (focusing on speech with the same person, in a new situation).
- Including teens and young adults in the planning process is especially important. To help increase motivation it may be necessary to first focus on speaking goals that are important to your teen even if they may not be the most important goals for you!

3. Prepare in advance

- When possible, give friends and family members some guidance in advance about how to best interact with your child.
- For example, it may be helpful to ask them to refrain from immediately asking your child questions, and instead follow their lead and comment on positive aspects of your child's behavior in a way that does not necessitate a verbal response.
- Remind speaking partners to wait at least five seconds for your child to respond and to not interpret your child's non-verbal responses. Both of these things seem simple, but can be hard to do!

4. Encourage thoughtful greetings

- Well-meaning significant others may be quick to give a warm greeting and ask a question like, "How are you?" immediately putting a child with SM on edge. Even saying "Hello, Lila!" places an expectation of speech on a child (i.e., returning a greeting).
- · Instead, have your babysitter or your family friend say something like: "It's so good to see you this morning, Lila. I'm so glad we can hang out together today."
- For many children with SM, giving greetings and using social niceties (e.g., please thank you, I'm sorry) are extremely anxiety provoking and are often considered more advanced treatment targets. Therefore, while a goal like "saying hello to a neighbor" seems simple, it is usually better to wait to focus on greetings and other social niceties until a child is more comfortably engaging in other forms of speech.

5. Initially, avoid questions...start with descriptions, reflections, and labeled praise

- · Use the same foundational strategies you use in your one-on-one parentchild time to allow your child a chance to warm up and get comfortable in new settings and with new people. Encourage others to use the same language and phrasing.
 - Remember, descriptions narrate your child's behavior, reflections paraphrase or summarize things that they have said, and labeled praise highlights specific things they are doing well.

- For example, "Great job picking the MagnaTiles to play with today (labeled praise). I see you are putting the green triangle on top of the big red square (description). I like how carefully you are building (labeled praise)!" or "I see that you brought your blue soccer ball to practice today (description). Great job putting it down and waiting patiently for practice to start (labeled praise)!" or "You said you want to have cookies for a snack (reflection). Thanks for letting me know your choice (labeled praise)!"
- For an adolescent you may say something like, "Wow, this YouTuber is so funny. Thanks for introducing me to this channel (labeled praise)." or "You are so good at this video game (labeled praise). You just flew by that person (description). Even with hours of practice, I think I wouldn't even be half as good."

6. When your child seems more comfortable, start by asking forced-choice questions

- Allow for a warm-up of at least five minutes to establish your child's comfort in a new setting or with a new person before moving on to questions. However, if your child is very anxious or just starting out, they may need a longer warm-up period.
- The type of question you ask of a child with SM is very important. Yes/no questions (e.g., "Do you like school?") often lead to nonverbal responses like nodding. Open-ended questions (e.g., "What's your favorite part about school?") may be too complex for some kids who are afraid of saying the wrong thing and require much more sophisticated verbal formulation skills. On the other hand, forced choice questions (e.g., "Do you like history or chemistry better?") are an ideal starting point since the script for the answer is already available. This additional scaffolding increases the likelihood that an anxious child will give a verbal response.
- Even if you begin asking a yes/no question, you can always add "or something else" to the end to turn the question into a forced choice.
 - "Would you like pretzels? ... Or something else?"
 - \circ "Did your team win the game today ... Or did the other team win?"
- · You can also give forced choice questions with multiple response options:
 - "Would rather play Minecraft, play Roblox, or do something else?"
 - "Do you think the answer is George Washington or Thomas Jefferson or are you not sure?"

| Types of Questions | | |
|---|---|---|
| Yes/No Questions | Forced Choice Questions | Open Ended Questions |
| Straightforward questions that can be responded to with "yes" or "no" Although these can occasionally be helpful if a child is just starting out or is extremely anxious, they should generally be avoided as they give limited opportunities to practice speaking and often result in non-verbal responses. | Multiple choice questions These are a recommended starting point for asking questions when a child is anxious. They facilitate speech while reducing processing demands. | Questions that require an independently generated response Open ended questions are generally more complex, leave more room for error (which can increase anxiety in those with concerns about perfectionism and making mistakes), and may require more elaboration. Answering open ended questions is a more advanced speaking skill. |
| "Are you in middle school?" "Do you like tennis?" "Is it okay to start now?" "Do you want a snack?" | "Are you in 6th grade or 7th grade?" "Do you like tennis or is it only okay?" "Are you ready to start now or do you want to wait a minute?" "Do you want an apple, a banana, or something else?" | "What grade are you in?" "How is tennis?" "When do you want to start?" "What kind of fruit do you want?" |

7. Wait 5 seconds

- If your child is asked a question and does not answer, wait at least five seconds. Five seconds can feel like a really long time, especially if someone else is waiting for an answer, so it often is helpful for you to get used to it by practicing slowly counting to five in your head!
- After five seconds, repeat the question. If it was an open-ended question, try turning it into a forced choice question instead. It's important to give your child time to think, process, and work up the courage to speak before answering!
- Even if you feel nervous or uncomfortable waiting in silence, try not to let your child see your nervousness as that can make them feel more anxious too!

8. Avoid mind reading

- Children with SM are often masters at non-verbal communication. If you see your child pointing or shaking their head say, "I see that you're nodding your head. Please tell me with your words. Do you want pretzels or a different snack?"
- It is also important to do this with teens, and it is sometimes helpful to include humor: "I see you nodding, but I can't seem to remember what that means....You know I'm waiting for those words." Alternatively, your teen might appreciate a more matter-of-fact explanation. For example, "I'm asking again because I'm looking for you to answer with your words. Remember every question is an opportunity to challenge yourself, and I don't want you to miss out on these opportunities for growth."

9. Responding to verbalizations

• Think about how you (and others in the environment) respond when your child accomplishes a particular speaking goal. Caregivers often make two common mistakes: responding with overly enthusiastic acknowledgement or not giving any acknowledgement of the child's response at all. Many children with SM do not like to be the center of attention and find exaggerated or overly enthusiastic responses to be very uncomfortable. However, in responding to a question or sharing an idea, your child just did something really hard and some recognition of that is important!

- Simple and casual labeled praise is usually a great way to let your child know that they've done a good job and increases the likelihood that they'll respond similarly next time.
- For instance, you might respond "Thanks for letting me know that you want to play Uno today," "I bet Mrs. Washington appreciated how clearly you asked her about the due date for your paper," or "It was really cool that you ordered your own pizza."
- Keep in mind, that for some children even simple labeled praise feels uncomfortable. In this situation, try responding to verbalizations in other ways (e.g., a quick thumbs up, a smile, a pat on the back).

11. Giving rewards

- It can be incredibly helpful to pair practice brave talking with positive reinforcement, including tangible rewards (e.g., stickers, small prizes, extra privileges) that can help increase motivation to face fears, especially at the beginning of treatment, and maintain momentum.
- Reward systems also can work for older children and teens, with some developmental tweaks. Whereas younger children may benefit more from immediate reinforcement (i.e., something that can be earned right away), older children may wish to earn "points" to work for a larger reward that can be earned over time, which also can help teach them the value of hard work and saving.
- With children of all ages, it is important to be make sure that the rewards you are offering are sufficiently motivating and that the expectations for earning the reward are clear. It is also important to select rewards that they don't already have easy access to.
- · It is a great idea to involve older kids and teens in a discussion about what types of rewards or privileges they might enjoy. Caregivers should always reserve the right to decide how much points/work will be necessary to earn those rewards. Rewards do not have to cost any money and can include things like a family movie night, a favorite meal, or extra screen time.
- Rewards are generally a shorter-term intervention. Reward systems can be faded out or adapted to address harder challenges as your child makes progress in meeting their communication goals.

11. Using videos to communicate

- Before speaking to someone new face to face (whether in person or virtually), some children benefit from first sending short videos or audio clips back and forth, which can help them get comfortable with the idea of others hearing their voice.
- Consider having your child create a video at home, showing off something they are really interested in (e.g., a favorite Lego set, a pet, a TikTok video). With your child's knowledge, send the video to someone with whom your child is ready to work on brave talking. Have that person send a video back, including a few forced choice questions for your child to answer. Record your child answering the questions, and maybe asking a question of their own, and send that video back.
- · Repeat this as many times, and with as many new people, as seems helpful!

12. If others ask why your child does not talk

• Politely correct them and say, "Sam does talk. She is building her brave muscles and practicing getting comfortable talking in different places" or "Actually Jose talks all of the time at home, and he is working on talking in school too."

13. Be mindful of other worries and fears

- Your child with SM also may experience worries, fears, and big emotions that are triggered by other situations (e.g., being alone, being the center of attention, being overstimulated, feeling left out, experiencing frustration when things don't go their way). To the extent possible, when working on speaking goals try to make sure that your child isn't also feeling anxious or distressed about something else at the same time.
 - For example, if your child is afraid of dogs, your neighbor with two energetic puppies running around, might not be the best person with whom to practice brave talking, at least at first.

14. Empathize and encourage

• It can be frustrating and challenging for parents to see their children struggle to speak and watch them experience emotional distress. Though it can be hard, stay calm! Do not reprimand or punish your child for not talking, and avoid using guilt to try to get them to talk.

- Anxious children do best when parents empathize with and validate their emotions while simultaneously offering them encouragement and expressing confidence in their abilities.
 - "I know you feel scared to order your own drink, and I know how brave you are so, I know you can do it."
 - "It is really hard to meet a new teacher for the first time. I used to worry about that when I was your age. We'll say hi together. You've met lots of new people recently, so I know you'll do a great job meeting Ms. Johnson too."
- · We recommend using "and" not "but" when providing such validating statements. "But" tends to disregard the empathetic portion of the statement and might seem "too pushy" (e.g., "I can see that this is really hard for you, but I know you will find the courage to tell the pharmacy staff your birthday.").

how to address concerns with family and friends

How caregivers can approach the topic of selective mutism with their family members and friends

Having a conversation with your extended family members and family friends about SM may be very helpful to promoting progress, especially in the following situations:

- · They want to better understand your child and their experience with SM
- You are hoping to include them in brave talking practices since your child doesn't yet speak with them
- They are frequent caregivers and may need to help carry out brave talking practices in public or at school
- They are trying to encourage your child to speak to them in a way that doesn't seem to be helpful

In preparing for these conversations, keep in mind that family members and friends will likely not know much about SM or may be relying on inaccurate information (such as that your child is just "shy" and will "grow out of it" or that your child is being disrespectful by not responding). If your family includes other individuals with social anxiety and/or undiagnosed SM, some might feel that your child's limited communication may even be expected and that they should not be asked to do anything outside of their comfort zone.

Be prepared for the other person to experience an emotional response during the conversation. If your child speaks comfortably to the relative or friend, they may be confused that speech is an issue elsewhere and think that you are blowing things out of proportion. If they have never heard your child talk, they might be hurt and/or frustrated that their attempts to engage your child have not resulted in an increase in communication. Many will want to help but will be unsure as to how.

The first step is to help your loved ones understand the diagnosis of SM. Many caregivers find it important to stress that the lack of communication is due to anxiety and not due to dislike of the family member, disrespect, or oppositionality. Sometimes it's helpful to illustrate this using another (potentially better understood) fear. For instance, someone who has a phobia of heights acts differently when they are safely on the ground than when they are at the top of a tall building or overlooking a cliff, but they aren't being purposefully rude if they push past you as they try to get to the elevator. Their behavior is driven by fear, and that is also true of individuals with SM.

Consider talking with your loved ones about the pattern of avoidance that was shared earlier in this toolkit and/or any other resources you have found to be helpful or that your child's treating professional has recommended. Seeing the difference between your child at their most comfortable and your child in an anxiety-provoking situation may highlight your child's experience in a more meaningful way for your family members and friends. You might share a video of your child talking at home to those that the child has not yet spoken with and a video of your child frozen at school drop-off for those who have only seen your child comfortably engaged in conversation at home.

The inclination to "rescue" and/or not put unnecessary pressure on your child is natural, so you might need to remind your family members and friends that you're taking a different approach now. One way to guide others to discontinue rescuing is to offer examples of the ways that you have also been in the habit of rescuing and what you do differently now. Explain to them the current communication goals your child is working on and how you're trying to arrange these practices such that they start out easier and build up with time and success. Conversely, you may need to remind others of the importance of taking things slowly if they push for speech too enthusiastically.

Sharing about the strategies you've found to be helpful so far helps your loved ones feel like they have a concrete way to help. You could model using forced choice questions and suggest forced choice questions that they might ask your child. You may even directly say something like, "Aunt Jasmine, please ask Andre if he had a soccer game today or a basketball game today." You might explain the importance of waiting 5-7 seconds after asking a question. You could share that communication has come easiest in one-to-one interactions instead of in front of groups and arrange for opportunities for your child to spend small amounts of one-on-one time with a relative (perhaps with you present at first and then just with the two of them). You could model how to praise your child without overwhelming them.

When someone employs strategies that don't seem to be helpful in practice and/or aren't consistent with your treating professional's therapeutic recommendations, you'll likely need to provide some constructive feedback. This can be hard; we tend not to correct other adults regularly, and no one wants to hurt anyone's feelings! One helpful way to offer feedback is first recognize their good intentions and couple it with a specific strategy that should be used instead. For instance, you might say something like "I know you really want to help Talia get more comfortable talking to you, and I can see how hard you've been trying. You're always prepared with questions to ask her when we get together. One thing we've been learning as we've practiced this is that she needs about 5-10 minutes to warm-up before talking when someone new comes over. I know she wants to tell you about her art class though. She made something amazing yesterday. When I signal you, can you ask her if she sculpted a flower or painted a picture of a panda? Until then though, it would be most helpful if you didn't ask her any questions right away."

One last thing to be aware of: there are some people with whom and places where your child will continue to struggle to speak, even as they progress through treatment and achieve success in speaking on other settings. This is called "contamination." There is an established social dynamic, and speaking in this context can be particularly anxiety provoking because it is very unexpected. Moreover, individuals with SM may worry that the "contaminated" person will make a big deal about hearing them talk, leading to extra attention and possible embarrassment. Since your extended family members, neighbors, and close family friends tend to have long-standing relationships with your children, they can certainly be "contaminated." This does not mean that your child will never talk to these people, it just means that they likely will have more success practicing speaking with other people first, and that more thought will need to be put into creating just the right situation to practice establishing speech with the "contaminated" person.

support at school

Seeking support from school personnel is also an important step in helping your child conquer SM. Our children spend large portions of their days at school and are expected to carry out a number of important communication tasks in that setting (e.g., verbally engaging in academics, asking for help when necessary, socializing with peers, contributing to group projects, and getting teacher permission to use the restroom), so it is important to inform the school about their SM symptoms and to work together to set up a plan and implement strategies to support your child's speech and build their self-advocacy skills in this setting.

By voicing your concerns to the school, they will likely help you to determine accommodations (changes in the day-to-day routines so that your child can still participate despite their limitations in communication) and interventions (specific strategies that will be used to encourage growth toward identified goals). If your school team is new to SM, they may wish to review our companion guide: the SMA Educators Toolkit.

Knowing what to say and how to communicate with your child's school about their SM diagnosis can be challenging. The following template may be a helpful guide. Sending a letter like this – that formally puts your concerns in writing and calls for a school meeting, is the first step in establishing a school-based support plan.

Letter Requesting Classroom Accommodations/ Special Education Services

This letter is typically sent to the school principal, special education coordinator, classroom teacher, and school psychologist or social worker, before a child has formal school-based support in place.

I am writing this letter on behalf of my child, [child's name], who is in [teacher's], [grade] class at [school name]. [Child] was recently diagnosed with selective mutism by [name of treating professional]. Selective mutism is an anxiety disorder that makes it difficult to communicate verbally in many social situations. [Child] is able to speak comfortably with our family at home, but due to overwhelming anxiety, struggles to speak at school. I would like to request a meeting with the special education team to discuss the potential for accommodations and interventions at school in order to best meet [child's] educational needs. In particular, I am concerned that [child] [include 1-2 sentences to reflect your child's specific situation].

Children with selective mutism require specific interventions in the school setting to help them overcome their anxiety and ensure they are able to most effectively access the curriculum, learn new material, and participate in classroom activities. This includes working with a designated staff member or interventionist who is able to encourage [child's] speech, support [child] in "brave talking" practices at school, and facilitate communication among all team members and between school and home.

I look forward to hearing from you within the next five business days to schedule a meeting at a mutually agreeable time in order to discuss these issues and consider accommodations and interventions to best support [child] at school.

In the United States, the Individuals with Disabilities Education Act (IDEA), entitles students to receive special education and/or related services if it can be determined that the student has a disability, and as a result of that disability, needs special education to make academic progress. According to the Department of Education, any public school student who is eligible for and receives special education and related services must have an Individualized Education Program (IEP). Students who do not meet the criteria spelled out by IDEA may still qualify for help at school under Section 504 of the Rehabilitation Act of 1973, also known as "Section 504" or "a 504 Plan."

Comparing IEPs and 504 plans

Individualized Education Program (IEP)

- Disability must fall under one of 13 specific categories specified in the Individuals with Disabilities Education Act (IDEA)
- For eligibility determination, schools typically require a comprehensive evaluation to be completed and data collected from intervention provided through a Multi-Tiered System of Supports (MTSS).
- Individuals with SM often qualify under the category of
 - "Other Health Impairment"
 - "Speech/Language Impairment"
 - "Emotional Disturbance/Emotional Disability"
- The SM symptoms must affect the child's educational performance and/or ability to access and participate in the general education curriculum
- · An IEP includes individualized programming that may be provided in the general classroom setting, in a small group setting, or one on one
- Allows for access to specially designed instruction, individualized goals related to the area of a child's disability, and classroom or testing accommodations
- Includes clearly laid out goals and objectives based on child's needs

 Part of the Rehabilitation Act of 1973

504 Plan

- Individual must have a perceived or diagnosed disability that limits one or more major life activity (as a mental health condition, SM typically qualifies)
- The disability must interfere with the child's ability to learn/fully participate in the classroom setting
- · A 504 plan provides accommodations, but not direct services

Regardless of whether your child has an IEP, a 504 plan, or less formally documented supports, here are some important considerations for maximizing speaking success at school.

Pick a point person

It will be important to identify a "point person," sometimes referred to as a key worker or interventionist, who will be the primary person responsible for implementing services for your child at school. The ideal interventionist may vary depending on the child's age, symptoms, the district's requirements, and any co-occurring concerns. Some potential candidates to consider may be a school psychologist, school social worker, school counselor, school speech pathologist, school interventionist, special educator/ESE teacher, or classroom aide. While classroom teachers play an important role in intervention plans, due to their responsibilities in the classroom, they are not always the best choice for providing a high level of one-on-one support. It is more important to pick a staff member who both has the time to dedicate to your child and whose personality is a good fit for your child. Previous experience working with students with SM is less important as long as the interventionist is willing and able to learn more about SM and the best practices (e.g., through consultation with you or an outside mental health professional working with your child). It is helpful if the child is already verbal with the interventionist. Think also about the interventionist's scheduling availability. One-to-one meetings are typically necessary at the onset of intervention, and it may be better to meet in more frequent but shorter bursts (e.g., four times per week for fifteen minutes) rather than one longer meeting per week.

Get off on the right foot

Once an interventionist is identified, there are two important next steps: 1) establishing speech with them and 2) helping your child to understand what will be asked of them during their intervention time.

Though you will have to hand off a large portion of the in-school support to the school team, you can absolutely help in these goals! If your school permits visitors, you could consider coming to the school to assist in helping your child first speak in front of and then directly to the primary interventionist. Select activities and/or conversational topics that your child will enjoy (as opposed to academic tasks).

Both the caregivers and the interventionist may wish to have conversations with the child to help them grasp what will be asked of them as brave work in the school begins. Talk about how most tasks get easier the more they

are practiced. This is certainly true for most academic skills, but also likely applies to any extracurricular activities your child is involved in. Being brave in school will probably feel pretty similar. It may be challenging at first, but with practice, it will get easier.

For older children and adolescents, you may wish to talk about how anxiety works in the brain and how we can retrain our brains to respond differently in anxiety-provoking situations through repeated practice. You can also reiterate that both you and the school team are there to help them and will work hard to make sure that they aren't asked to do anything that is too hard.

Scaffold

Talking goals at school should be scaffolded so that practices are organized in a stepwise format from easiest to hardest. In the best case scenario, the child (if old enough) can be included in the development of the goals. If you are supporting a teenager, then it is even more important that they are involved in creating, and sometimes, even tracking their own goals. Teenagers will need to feel a sense of agency over what they are being asked to do, and their collaboration in setting the goals and their motivation to complete them is a key part of this. Since each person's experience of anxiety is unique, each person's goals to tackle their anxiety will also be unique. The child should have every chance for success with each practice. This will allow them to feel accomplished and be more willing to progress into more advanced goals.

You'll notice that some of these goals may be best met when services are completed in a separate location (with no one else there), whereas others would be better accomplished if the interventionist pushed into the classroom, lunchroom, playground, etc. The interventionist may need to be flexible with the setting of the meetings based on the specific needs and goals of each student. Below is a list of sample goals rated by difficulty, but please remember that each child and teen is different. What is "medium" for one child, may be "hard" for another. Setting your child/teen up for success is figuring out what are the just right goals for them.

| Possible Communication Goals at School | | |
|--|---|--|
| Easier Goals | Medium Goals | Harder Goals |
| Making sounds with the interventionist or teacher Answering forced choice questions from the interventionist or teacher when alone with them Answering openended questions from an adult when alone with them Answering questions from a friend when alone Asking a question to a trusted communication partner when given a script of what to say Talking with a trusted communication partner in a new place (e.g., another private office, in their classroom when no one else is there) | Speaking to a trusted communication partner in front of another person or in a small group Playing verbal games with a few friends at recess Participating in a small group of students—in the classroom, in a social skills group, or in a speech therapy group Speaking to different adults around the school—e.g., to borrow supplies from another teacher, to get a bandage at the front office, to order lunch in the cafeteria | Answering when called upon in class Giving a speech in class Greeting someone with a "hello" or "good morning" Using social niceties like "please" and "thank you" Demonstrating selfadvocacy skills like asking for help Seeking out adult assistance when sick or injured |

Collaboration with Treating Professionals

If your child is meeting with a mental health professional, you may wish to invite this provider to consult with the school team. This may involve the treating professional joining in on 504 Plan/IEP meetings and periodically scheduling phone calls to discuss progress and goals. Some treating professionals are able to provide direct intervention at the school or during

the school day as well. This often is a particularly effective way to help a child learn to be brave at school. The treating professional may be able to assist the child in speaking to their teacher, in speaking to their friends, in helping teachers to collect necessary assessment information, and moving towards other speaking milestones. The treating professional may also answer questions from the interventionist/education team and offer suggestions to educators about additional strategies to consider.

There is a great deal of variability with regard to what a school can or will provide a student with SM, even within the framework of a 504 Plan or IEP. A short list of possible accommodations and interventions is below. For a more comprehensive list, see our website. It is important to remember that progress should be reviewed regularly and the level of accommodation should be revised accordingly; as students meet initial goals, new goals should be identified and prioritized.

Possible Accommodations

- Schedule one-on-one meetings with any new teachers before the school year starts. The purpose of these meetings is for your child to establish rapport with, and begin talking to their new teacher(s).
- · Class placement with 1-2 peers with whom the child is already able to speak.
- · When a student is not yet able to communicate verbally
 - Child can nonverbally indicate preferences and needs.
 - Adults should avoid placing speech demands on the child.
- · When a student is able/ready to start practicing speaking
 - \circ Teachers will use forced-choice questions.
 - \circ Teachers will wait 5-7 seconds the student to respond.
 - Teachers will reinforce speech with some type of reward system/behavior plan.
- · When focusing on speech with peers
- The school will help parents identify children for playdates outside of school.
- Interventionist will facilitate play and verbal interaction between student with SM and a preferred friend.

- · To effectively track progress
 - The interventionist will maintain a behavior chart/daily report card (DRC) documenting all instances of targeted speaking behavior. This document will be shared with caregivers, school team members, and others working with the child every Friday to communicate progress.
- Accommodations for bathroom use
 - Child and teacher will agree upon a non-verbal signal to communicate the need to go to the bathroom.
 - o Child will be prompted to use the bathroom at specific intervals every day.
- · Accommodations for assessment
 - Parents will be trained to administer some assessment protocols at home and record child responses.
 - A comfortable communication partner (e.g., previous teacher, interventionist) will administer all assessments.
 - Non-verbal methods of assessment will be permitted until the child is able to effectively participate verbally.
 - Assessments windows will start with the opportunity for a short warm-up such as engaging in a conversation about a preferred topic or playing a preferred game so that the child is already talking.
- · Outside consultation
 - School team will participate in consultation with an outside treating professional to learn the strategies being used to help the child with their speaking goals; this may include a training session where specific skills and strategies are reviewed.
 - School team should collaborate with the outside treating professionals on a regular basis (e.g., weekly, biweekly, monthly) depending on the level of impairment.

Possible Interventions

• Child will participate in a "lunch bunch" or other social based group, where the child has an opportunity to practice speaking in a small group, often led by a school social worker, psychologist, special education teacher, or counselor; ideally, this would start with peers the child already speaks to and then would vary the children over time. • Child will receive one-on-one counseling from a school psychologist or social worker with goals of facilitating and extending speech in various environments and with new people at school.

At times, schools may be hesitant to provide support for a child with selective mutism, particularly if that child is making progress academically and meeting learning benchmarks. When this happens, schools are typically well-intentioned, but may have limited resources, not fully understand selective mutism, or be unsure about how to best support your child. In these situations, we encourage you to be polite, but persistent in requesting support. First, if you haven't already done so, provide the school with resources – like SMA's Toolkit for Educators – to be sure that they truly understand what SM is. Secondly, share specific examples of how your child's SM is interfering with their ability to fully participate in the classroom - regardless of their "grades" or academic performance. This might include a teacher not being able to accurately assess a child's reading skills, an adolescent not being able to take foreign language classes, a child not being able to ask questions when they don't understand a concept or assignment, or a teenager not being able to participate effectively in group projects. If staff in your child's school are unresponsive, you may need to contact district-level personnel, such as school system's Special Education Coordinator or Director of Behavioral Health Services (note that these titles can vary from place to place). Lastly, the support of an outside professional, including professional documentation of a child's needs, can sometimes assist schools to make forward progress with anxiety-related goals. This might come in the form of a communication from a treating professional already working with your child or may involve hiring an educational advocate. An educational advocate is someone with extensive knowledge about special education programs, 504 Plans, IEPs, and school-based support that students can receive who can help you work with the school to acquire the resources your child needs.

For more information on the special education process and school-based supports, visit our website.

selective mutism in the community

There are plenty of situations in public settings that may require your child to verbally engage. Practicing in public is a **great** way to foster new bravery and encourage functional communication in real-world settings. However, this process often involves a bit more than a simple statement like "go and tell the server your order." This section will review ideas to help foster successful brave talking practices in the community.

Heading off into a community practice can feel overwhelming (for both youth with SM and for their caregivers)! Most caregivers have been in a situation where a person unexpectedly shows up out of nowhere and asks a question to your child. Most caregivers of youth with SM also have experienced the comments that follow when their child is unable to readily produce an answer (e.g., "I used to be shy too when I was young," or "You don't need to be scared of me... I'm really nice.") and the pressure to jump in and respond for their child. Although practice likely will be a little uncomfortable, everyone will feel more confident with preparation.

Plan to start community practices with a small warm-up period where the child is only expected to speak to a caregiver or another established communication partner in the less familiar setting. The first speech expectation in the new setting should not be with a new person, as this may too much, too soon.

Be sure to pick out a goal that is just outside your child's comfort zone. For instance, if they've been answering forced choice questions from their teacher at school, they would likely be ready to try the same skill in public. Here are some ideas to consider along a sample trajectory that moves from easier talking goals to harder talking goals:

- Speak to caregivers in public
- Direct a response to a speaking prompt posed by a caregiver to a new person (e.g., The caregiver may say, "Please tell her if you want lemonade or apple juice.")
- · Respond to a forced choice question from a new person

- · Respond to an open-ended question from a new person
- Initiate/ask a new person a question (with help in developing a script of what to say)
- · Get others' attention (e.g., saying "excuse me")
- · Using greetings and other social niceties (e.g., saying "hello," "please," and "thank you")

As we've already outlined, using the right type of question is a really important way to set your child up for success, but most people in the community won't know to pose their questions in a way that will most effectively encourage speech, so they might need a little help from you. Although uncomfortable, offering a brief explanation with a direct request of what you'd like the other person to say can be helpful and ease a little bit of the tension. "We are practicing talking to new people. My son is new to ordering his meal. Can you please ask him if he'd like a grilled cheese sandwich or a hamburger?"

Most individuals with SM feel unsure of what to do and say in social situations, so it can be incredibly helpful to give your child a script of what to expect and what to say. For instance, you could say something like "When we get into the bakery, I will order first. I'll also tell the employee that you're ordering a cookie. Then, they will ask you what kind you want. Let's figure out what you're going to pick now, so it will be easier to remember when we get inside." After your child knows what will be expected and what to say, practice ordering before going into the store. It may also be helpful to have them practice ordering to you after stepping into the store, but before approaching the counter.

Caregivers should come in with a Plan B, a Plan C, and maybe even a Plan D and Plan E.

| Goal: Ordering ice cream | |
|--------------------------|---|
| Plan A | Responding to an open-ended question from an employee like, "what do you want?" Responding to an open-ended question from an employee like, "what do you want?" |
| Plan B | Caregiver can prompt the employee to repeat the question (e.g., "Can you please ask her what she wants to order again?") |
| Plan C | Caregiver can prompt the employee to use a forced choice (e.g., "Can you please ask her if she'd like a banana split or a chocolate shake?") |
| Plan D | Caregiver can ask the question directly to the child (e.g., "Please tell me what kind of ice cream you want.") |
| Plan E | Take a few minutes to decompress, practice ordering away from the counter, and come back to try again |

Be sure to bring along your reward system when practicing brave talking in the community. When your child completes the goal, it's important to deliver the sticker, point, or tally mark that you've promised. Picking a naturally motivating setting in which to practice—like an ice cream parlor, the zoo, an arcade, or a craft store—may also help to increase your child's motivation.

Sometimes, people "pop-up" and start asking questions - even though this was not part of your planned communication goals for the outing. If you have not yet had much success in planned/scripted community practices, responding to people unexpectedly might be an unrealistic goal. In such situations, it often is appropriate to let your child know that you will handle these questions until they are ready. However, if you are really making good strides with community practices, it might be a good idea to let your child try to answer the question (they might surprise you after all this other brave practicing!). One helpful idea is to reformat the question into a forced choice option. For example, if the "pop-up person" asks "What's your name?" you could ask "Are you Evan or Pinocchio?"

This all might feel a little silly or uncomfortable at times. Try to tolerate it; by using these strategies, it may mean an increased chance of success for your child! Keep in mind you will not likely see this particular employee again any time soon and that you are providing a great model of overcoming discomfort for your child.

playdates and hanging out with peers

Caregivers understandably have many questions about how to best support children with SM to increase verbal communication with other children. While it may be possible for caregivers to "coach" other adults in asking forced choice questions and waiting five seconds for a response, it is much harder to guide peer interactions in this way. Here are some tips and strategies to help.

First of all, set your goals for the playdate and make sure that you have realistic expectations! Remember, that for some children a playdate during which they are able to play reciprocally with a peer, even if they do not say a word, can be considered a success. For others, success might even be defined as simply playing near another child! Some children may be working on responding to peers' questions whereas others might be focused on more complex goals like initiating speech or speaking in a group setting.

Next, identify potential playmates. Think about peers who will be a "good match" for your child, both in terms of interests and personality style. It can be helpful to get input from your child's teacher about whether there are particular classmates with whom your child seems more comfortable and connected. When setting up a playdate, it will likely make things go more smoothly if you let the other child's caregivers know what to expect.

At first, plan playdates in places where your child is already very comfortable and ideally, has already spoken. A playdate with a new peer in a new place may be too overwhelming if you are just starting these practices. Involve your child in planning for the playdate and choosing activities to get them excited and help them feel more in control. For many anxious children, providing a higher level of structure during playdates can help reduce distress and make it easier to work on brave talking goals. For children who are more behaviorally inhibited, it may be too much to expect your child to play with someone new, figure out what to do, and practice speaking all at once.

For younger children, at the beginning of a playdate, set out 2-3 toys that do not involve speaking demands, to allow for a warm up period. During this time, you may help your child and their friend get engaged by giving them both labeled praise, narrating their play, and reflecting speech. As your child gets comfortable, you may want to start asking forced choice questions or prompting them to speak directly to their friend. If the other child's caregiver is present, you may need to give them a gentle prompt or reminder to not ask too many questions too quickly. After a warm up period, it is often helpful to transition to a game or activity that involves speaking demands and is more structured. Games like Go Fish and Guess Who help set clear expectations for speech. Similarly, active games like Red Light Green Light and What Time Is It Mr. Fox? offer the same benefits in the context of physical movement, which can often help reduce playdate jitters. Regardless of the activities you and your child choose, be mindful of the level of speaking required and make sure that it is consistent with your child's brave talking goals.

When working on social goals with older children, use technology to your advantage! It may be easier for your child to establish communication with a peer through text or social media before transitioning to speech in person. Playing a video game together online with peers also may help scaffold speech. While older children tend to have less structured playdates, you can use many of the above principles for an older child. Consider developmentally appropriate semi-structured activities such as baking, building a Lego set, or doing a craft together. Many board games are still engaging for older kids and teens, so you may consider having a small game night with one or two preferred peers and special snacks.

older youth with SM

If not specifically addressed, all the tips and strategies in this manual also apply to tweens and teens. However, it is always crucial to adapt so you are using developmentally appropriate language and activities.

Some key aspects of working with teens:

- Many tweens/teens benefit from additional education the function of anxiety and how anxiety impacts their brains and bodies physiologically.
- · Likewise, teens are more likely to be aware of their unhelpful thoughts surrounding speaking goals (e.g., "Everyone is going to laugh at me if I get the answer wrong in class.") and can be engaged in discussions and strategies to challenge those unhelpful thinking patterns.
- Collaboration and transparency are important. Older kids and teens need to be involved in goal setting and decision making. If they don't feel agency over the process and have agreed to goals, then the likeliness that they follow through decreases. This is especially important as older children may need to be able to work on meeting goals with more independence and less direct parental support than younger children.
- Motivation is necessary. Without motivation to work on talking goals, teens will struggle to persist through discomfort and often avoid any talking practice. While teens can still benefit from the chance to earn external rewards, you also may capitalize on their intrinsic motivation. For example, it can be helpful to highlight the things the teen may gain when they are able to talk more (more/better friendships, less anxiety about being called on in class, the ability to ask for help when needed, greater acceptance and inclusion in most social situations, more independence).
- Remember that teens have often been "practicing" not talking for longer. Therefore, it can take longer to unlearn that behavior. Be patient and know that any progress, even small, is progress! For some, adding in a medication can boost progress and might be an important component to a robust treatment program.

self-care for caregivers

Parenting is an inherently stressful job, even under the best of circumstances. However, it can become that much more difficult when children struggle. Their challenges become your challenges. In fact, caregivers often spend more time reflecting, worrying, and trying to problem solve when a child is struggling than children do themselves! This typically comes with lots of understandable, but sometimes uncomfortable and overwhelming, emotions. It is not unusual for parents of anxious children, and children with SM in particular, to periodically feel worried, scared, depressed, frustrated, and/or lonely. Often parents have been taught to feel that being fully there for a child means neglecting their own emotional needs, but not only is that not true, it generally ends up being less helpful for everyone! Parenting does involve a lot of hard work and sacrifice, but as a parent, it is just as important to care for yourself as it is to care for your child.

When a child is struggling, it is easy for a caregiver to start doubting themselves and their abilities as a parent. They may be quick to blame themselves for things that aren't going well and sometimes have been made to feel responsible for their child's challenges after hearing judgmental comments from others. Please know that your child's SM is not your fault. It is very likely that your child would have experienced many of the same challenges even if you had made different parenting decisions or given your child different opportunities.

In addition, many caregivers feel hopeless and may worry that their child's situation will never change. Although individual circumstances can vary, remember that research has demonstrated that the majority of youth with SM make clinically significant gains in response to evidence-based therapy and/or medication.

When uncomfortable emotions inevitably come up, using mindfulness or meditation techniques can help reduce anxious, sad, and other unhelpful thoughts. There are many apps that can guide you in mindfulness/meditation practice. Furthermore, try challenging anxious thoughts to help shift your perspective about stressful situations. For example, you may ask yourself questions like, "What is the true probability that what I am

worried about will happen? What are other outcomes? What has happened in similar situations in the past? If what I am worried about does happen, will it really be as bad as I think it is going to be? What tools and resources do I have to cope with this situation? What advice would I give a friend dealing with a similar challenge?" Often the answers to these questions can help you "reframe" anxious thoughts and guide you in thinking more realistically and less catastrophically.

Although the myriad aspects of managing your child's needs – from going to IEP or 504 meetings, to scheduling therapy appointments, to engaging in brave talking practices – can feel like a full time job, remember to prioritize carving out small moments to do the things that you enjoy. Whether this is exercising, catching up with a friend, reading a good book, connecting with nature, doing something artistic, or a completely different activity, scheduling time for yourself can seem like an unaffordable luxury, but will help you feel your best and ultimately put you in a position to be a better caregiver.

As those of you reading this likely are well aware, caring for someone with SM can be isolating. It can often feel like no one else really understands or can relate to your family's experiences. If this is the case for you, we strongly encourage you to seek connections with others in the SM community. There are many social media groups for caregivers of youth with SM as well as virtual, and in some places, in-person support groups. Additionally, especially if your emotions are negatively interfering with your well-being and impacting your life, please don't hesitate to connect with a treating professional of your own. It can be incredibly important for caregivers to have a safe place to discuss their own fears, worries, and concerns.

Lastly, remember to celebrate the small successes. Something as simple as waving to a friend, joining a group activity, ordering a meal independently, speaking to a new babysitter, or having a successful playdate may represent a big success for your child! Acknowledge these "victories" even when they seem small. Remember that the path forward won't always be linear or smooth – in fact, periodic setbacks are to be expected - but that over time, a series of small victories accumulates into meaningful progress! Even as you look ahead to tackle new goals and challenges, appreciate where your child has been – and take a moment to praise yourself for everything – big and small – that you have done to help them on their journey.

helpful resources

Visit the Selective Mutism Association (SMA) website for resources including our online library and informational and inspirational videos (also available on our YouTube channel). SMA offers training/informational events such as the Selective Mutism Training Institute (SMTI) for Caregivers, an annual conference with a dedicated track of talks for caregivers, and a virtual caregiver support group that meets monthly. For additional assistance with school settings, caregivers may want to share the Educators' toolkit manual and the Educators' training webcourse with their child's teacher and school professionals. More information can be found regarding these resources on the SMA website.

Recommended Reading

Websites

Selective Mutism Association (SMA) www.selectivemutism.org

American Speech Language and Hearing Association (ASHA)

https://www.asha.org/public/speech/disorders/Selective-Mutism

Anxiety Canada

https://www.anxietycanada.com/

Effective Child Therapy

https://effectivechildtherapy.org/

Selective Mutism Learning University

https://www.selectivemutismlearning.org

Books for Caregivers of Youth with SM/Anxiety

Breaking Free of Child Anxiety and OCD: A Scientifically Proven Program for Parents

by Eli Lebowitz

Books for Caregivers of Youth with SM/Anxiety (cont.)

Can I Tell you about Selective Mutism? A Guide for Friends, Family and Professionals

by Alison Winters and Maggie Johnson

Growing up Brave: Expert Strategies for Helping your Child Overcome Fear, Stress, and Anxiety

by Donna Pincus

Helping Your Child with Selective Mutism

Dr. Angela McHolm, Dr. Charles Cunninghmam, and Melanie Vanier

The Ideal Classroom Setting for the Selectively Mute Child: A Guide for Parents, Teachers, and Treatment Professionals

by Elisa Shipon-Blum

The No Worries Guide to Raising Your Anxious Child: A Handbook to Help You an Your Anxious Child Thrive

Karen Lynn Cassiday

Overcoming Selective Mutism: The Parents' Field Guide

by Aimee Kotrba and Shari Saffer

Selective Mutism: An Assessment and Intervention Guide for Therapists, Educators, & Parents

by Aimee Kotrba

The Selective Mutism Treatment Guide: Manuals for Parents, Teachers, and Therapists: Still Waters Run Deep

Ruth Perednik

You and Your Anxious Child: Free Your Child from Fears and Worries and Create a Joyful Family Life

by Anne Marie Albano

Books for Adolescents

Being Brave with Selective Mutism: A Step by Step Guide for Children and their Caregivers

by Rachel Busman

Conquer Negative Thinking for Teens: A Workbook to Break the Nine Thought Habits That Are Holding You Back

by Mary Alvord

Learning to Play the Game: My Journey Through SilenceJonathan Kohlmeier

The Shyness and Social Anxiety Workbook for Teens, 2nd Edition by Jennifer Shannon

Books for Younger Children

Please visit the bookstore on our website for a complete listing of recommended reading for younger children and other books for selective mutism.

Research Articles About Selective Mutism Treatments

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Klein, E.R., Armstrong, S.L., Skira, K., & Gordon, J. (2017). Social communication anxiety treatment (S-CAT) for children and families with selective mutism: A pilot study. *Clinical Child Psychology and Psychiatry*, 22, 90-108.

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